



# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.  
*Reaching Out, Providing Help, Giving Hope*

## Facing the Issue of Death: The Family Perspective

*By Lynn P. Audette, M.S.W. Family Service Coordinator and Mindy Webb, L.C.S.W., former Family Service Coordinator*

One of the most difficult aspects of the position of Family Service Coordinator is learning that a child with CdLS has died. While it is a sensitive issue to face and discuss with families privately, we feel that it is important to bring the subject to a public forum. Our reason for including the topic, "causes of death," in this edition of Reaching Out is to provide direction to families seeking answers to questions about their child's health. For those of you who may find this material too upsetting to read, we encourage you to save it for a future time. It is with both desire to share information and trepidation to broach this subject that we set to explore some families' perspectives.

A recent issue of our electronic newsletter, Cybernews, posed the question to our readers, "Would an issue with this focus be of value to your family?" The numerous responses we received were positive. Many families shared that, although this topic is upsetting to think of, it would allow them to obtain useful information in caring for their loved one. Many parents indicated that learning more about the possible problems that face individuals with CdLS might cause them to be nervous or afraid. Many feel that gaining knowledge, no matter how upsetting, is imperative for the well being of the person with CdLS in their life. As has often been stated, "knowledge is power."

Jaime, mother of Sarah, shared, "...as grim as the topic is, it may give our family and doctors necessary information to keep our daughter as healthy as possible." Some parents have made reference to the need to look ahead and be aware of current issues that will help in preparation for both prevention and care. One mother indicated that the sight of a date of death associated with a child's name brought her to tears. Families have expressed concerns in the past that if a child is of similar age or development, there is an added need to know the cause of death. Allen, father of Alyssa, brought to light a common thread in the responses that we received. He states that, "articles regarding death causes should be welcomed because it will only help us all to prepare for the doorway into which we and our children all must pass, someday."

Personal sharing came from Kathleen and Don, whose daughter Michele died in 1992 at the age of 22. They were kind enough to recount their story. In Michele's case, there seemed to be no unusual signs that anything was wrong. She was in a good mood and displayed a good appetite the weekend prior to her death. On Monday, Michele's day program called and told Kathleen that she was not feeling well and vomiting, which was followed by dehydration and lethargy. The family contacted their physician, who instructed them to go immediately to the emergency room where a full evaluation was done. Exploratory surgery that evening showed that Michele had a bowel obstruction (volvulus) that could not be corrected. Michele passed



# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.  
*Reaching Out, Providing Help, Giving Hope*

away the following morning. Kathleen notes that Michele seemed to go from "what appeared to be normal to a very sick child and death, with no warning signs or symptoms within 24 hours."

"One thing that helped us was to know that she suffered very little." Kathleen also reflected on the positive: that a long hospital stay was not necessary and that Michele was able to enjoy her life until its end.

"Kathleen, Don and Michele were a team for 22 years. The three of us supported each other. After we lost Michele, we continued to support each other and to stay focused on the future and tried not to dwell in the past." Don and Kathleen also spent time with family during the holidays and tried to get out of the house more in lieu of sitting around and wondering "what if?" They did their best to keep busy and seek support from Foundation staff and other parents of the CdLS Foundation.

What we have learned from our many conversations with grieving parents is that each person grieves in their own way. Some parents, as Kathleen and Don, found strength within their own circle of family and friends. Others have found additional support and guidance by participating in support groups or grief counseling. Some parents have found unique ways to celebrate the memory of their loved one with CdLS. Planting a flowering tree in one's yard, writing heartfelt poetry, designing a very personal memorial service, or donating their child's wheelchair to another child in need are but a few ways of coping that people have shared with us.

Parents, family or friends provide their sad news to the Foundation office via telephone, letter or e-mail. News of loss has been shared with us immediately or in some cases, years later. There is no timetable for grief. The Foundation is available to families and caregivers at any time.

When notification is received from a family, several steps are taken to provide support and acknowledgement. All families are offered the opportunity to be matched with a family who has experienced a similar loss or to be in contact with Dr. Eileen Ahearn of the Clinical Advisory Board, a psychiatrist who specializes in these issues. Local Regional Coordinators are also contacted and share their sympathies with the family. Families may choose to include their child's name in the "In Memory" section of Reaching Out so others may also offer their support.

Dr. Laird Jackson, former CdLS Foundation medical director, is available to discuss medical questions with any family following the death of a child. Some parents have found it beneficial to talk about the circumstances, in order to gain a better understanding of the cause of their child's death.



# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.  
*Reaching Out, Providing Help, Giving Hope*

Alice, mother of Marilyn, expressed that following her daughter's passing, "I really didn't care what the cause [of death] was, but as time goes by, I think I would like to know." In the Kathleen and Don's case, learning that the nature of Michele's death was becoming more frequent among those with CdLS, brought them some reassurance that they were not alone in seeing no warning signs of her condition.

We would like to thank the families who so freely shared their personal experiences with us and in doing so, value not only the memory of their loved one but also offer knowledge to others. Alison, sister to Marilyn, put some of her thoughts to paper that seemed a fitting conclusion to this article.

"I cannot explain the love communicating through a silent language of touch. Holding hands on a guided stroll, taught me how to listen without ears, and love throughout the years."